bone study

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA

University of Minnesota
The Denver Children's Hospital
Children's Hospital of Pittsburgh
Children's Hospital at Stanford University
Dana-Farber Cancer Institute
Children's National Medical Center
U.T.M.D. Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Texas Children's Hospital
University of California at San Francisco
Seattle Children's Hospital & Medical Center
Toronto Hospital for Sick Children
St. Jude Children's Research Hospital
Children's Hospital of Columbus
Roswell Park Cancer Institute
Mayo Clinic
Children's Hospital - Minneapolis
Children's Hospital of Philadelphia
St. Louis Children's Hospital
Children's Hospital of Los Angeles
UCLA Medical Center
Miller Children's Hospital
Children's Hospital of Orange County
Riley Hospital for Children - Indiana University
UAB/The Children's Hospital of Alabama
University of Michigan - Mott Children's Hospital
Children's Medical Center of Dallas

Our new mailing address is:
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ccss@epi.umn.edu

Again, thank you for participating in the Long-Term Follow-Up Study.

This set of questions is specifically being sent to people who were treated for tumors, cancers or other diseases of the bone. We are hoping to learn more about how the treatments used for these diseases effect the patients years later. Your answers will allow us to better treat and anticipate the needs of patients in the future.

Please be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Person completing this questionnaire is:

_____
(Please print your full name)

Your relationship (mark one) ◯ Self ◯ Parent ◯ Other _____

Today's date: _____
(Month/day/year)

MARKING EXAMPLES

Below are some examples on how to fill out this questionnaire. Please look this over before you begin.

Example Please darken the circle of the number 0 – 10 that best describes your experiences:

If fatigue is no problem, fill in an appropriate circle.

1. **Fatigue** ..... No problem ●–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

If appetite has been a moderate problem, fill in an appropriate circle.

2. **Appetite changes** ..... No problem ⓪–①–②–③–④–⑤–●–⑦–⑧–⑨–⑩ Severe problem

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Example

Answer the question by choosing the answer that **best describes** your ability to do the activity **over the past week**.

You should choose the response "impossible to do . . ." if the activity is **something that you normally do** in your daily activities but are **now unable to do** because of physical limitations such as weakness, stiffness or pain.

If you do not perform an activity as part of your normal lifestyle you would choose the response "this task is not applicable for me" to indicate the item is not applicable.

If putting on a pair of pants is a little bit difficult and putting on shoes is extremely difficult, fill in the appropriate circles.

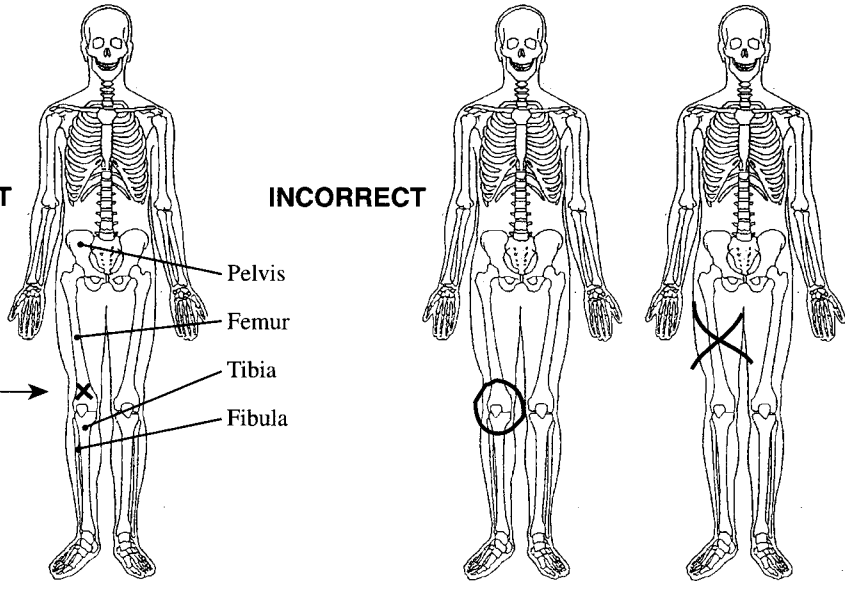
	This task is not applicable for me	Not at all difficult	A little bit difficult	Moderately difficult	Extremely difficult	Impossible to do
1. **Putting on a pair of pants is:**	①	②	③	●	⑤	99
2. **Putting on shoes is:**	①	●	③	④	⑤	99

Example

Please place an "X" on the skeleton where the tumor was located.

CORRECT **INCORRECT**

If your tumor was located in the lower part of the right femur (thigh bone), please place an appropriate "X". →



DIRECTIONS

We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life **at this time**.

Please darken in the circle of the number 0 – 10 that best describes your experiences:

Physical Well Being

To what extent are the following a problem for you:

A. 1. **Fatigue** ..... No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A. 2. **Appetite changes** ..... No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A. 3. **Aches or pain** ..... No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A. 4. **Sleep changes** ..... No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A. 5. **Constipation** ..... No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A. 6. **Nausea** ..... No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A.7a. **Females: Menstrual changes or fertility**.. No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A.7b. **Males: Fertility** ..... No problem ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Severe problem

A. 8. Rate your **overall physical health** ... Extremely poor ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Excellent

Psychological Well Being

A. 9. How difficult is it for you to **cope** today as a result of your disease and treatment? ..... Not at all difficult ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Very difficult

A.10. How good is your **quality of life**?..... Extremely poor ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Excellent

A.11. How much **happiness** do you feel?..... None at all ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ A great deal

A.12. Do you feel like you are **in control** of things in your life?..... Not at all ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Completely

A.13. How **satisfying** is your life?..... Not at all ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Completely

A.14. How is your present ability to **concentrate or to remember** things? ..... Extremely poor ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Excellent

A.15. How **useful** do you feel?..... Not at all ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Extremely

A.16. Has your illness or treatment caused changes in your **appearance**? ..... Not at all ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Extremely

A.17. Has your illness or treatment caused changes in your **self-concept** (the way you see yourself)?..... Not at all ⓪–①–②–③–④–⑤–⑥–⑦–⑧–⑨–⑩ Extremely

How distressing were the following aspects of your illness and treatment?

A.18. **Initial diagnosis** ..... Not at all distressing 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Very distressing

A.19. **Cancer treatments** (such as chemotherapy, radiation, or surgery) ..... Not at all distressing 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Very distressing

A.20. **The time since my treatment** was completed ..... Not at all distressing 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Very distressing

A.21. How much **anxiety** do you have? ..... None at all 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

A.22. How much **depression** do you have? ..... None at all 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

To what extent are you <u>fearful</u> of:

A.23. **Future diagnostic tests** (such as x-rays or scans) ..... No fear 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Extreme fear

A.24. **A second cancer** ..... No fear 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Extreme fear

A.25. **Recurrence** of your cancer ..... No fear 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Extreme fear

A.26. **Spreading (metastasis)** of your cancer ..... No fear 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Extreme fear

<u>Social Concerns</u>

A.27. How distressing has your illness been for your **family**? ..... Not at all 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

A.28. Is the amount of **support** you receive from others sufficient to meet your needs? ..... Not at all 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

A.29. Is your continuing health care interfering with your **personal relationships**? ..... Not at all 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

A.30. Is your **sexuality** impacted by your illness? ..... Not at all 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

A.31. To what degree has your illness and treatment interfered with your **employment**? ..... No problem 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Severe problem

A.32. To what degree has your illness and treatment interfered with your **activities at home**? ..... No problem 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Severe problem

A.33. How much **isolation** do you feel is caused by your illness or treatment? ..... None 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

A.34. How much **financial burden** have you had as a result of your illness and treatment? ..... None 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 A great deal

Spiritual Well Being

A.35. How important to you is your participation in **religious activities** such as praying, going to church? ..... Not at all important ⓪—①—②—③—④—⑤—⑥—⑦—⑧—⑨—⑩ Very important

A.36. How important to you are other **spiritual activities** such as meditation? ..... Not at all important ⓪—①—②—③—④—⑤—⑥—⑦—⑧—⑨—⑩ Very important

A.37. How much has your **spiritual life** changed as a result of cancer diagnosis? ..... Not at all ⓪—①—②—③—④—⑤—⑥—⑦—⑧—⑨—⑩ A great deal

A.38. How much **uncertainty** do you feel about your future? ..... Not at all uncertain ⓪—①—②—③—④—⑤—⑥—⑦—⑧—⑨—⑩ Very uncertain

A.39. To what extent has your illness made **positive changes** in your life? ..... None at all ⓪—①—②—③—④—⑤—⑥—⑦—⑧—⑨—⑩ A great deal

A.40. Do you sense a **purpose/mission** for your life or a reason for being alive? ..... None at all ⓪—①—②—③—④—⑤—⑥—⑦—⑧—⑨—⑩ A great deal

A.41. How **hopeful** do you feel? ..... Not at all hopeful ⓪—①—②—③—④—⑤—⑥—⑦—⑧—⑨—⑩ Very hopeful

The following questions are about activities commonly performed in daily life. Some activities will be extremely easy for you to do, others will be extremely difficult or impossible. Answer the question by choosing the answer that **best describes** your ability to do the activity **over the past week**.

You should choose the response "impossible to do . . ." if the activity is **something that you normally do** in your daily activities but are **now unable to do** because of physical limitations such as weakness, stiffness or pain.

If you do not perform an activity as part of your normal lifestyle you would choose the response "this task is not applicable for me" to indicate the item is not applicable.

	This task is not applicable for me	Not at all difficult	A little bit difficult	Moderately difficult	Extremely difficult	Impossible to do
B. 1. **Putting on a pair of pants is:**	①	②	③	④	⑤	99
B. 2. **Putting on shoes is:**	①	②	③	④	⑤	99
B. 3. **Putting on socks or stockings is:**	①	②	③	④	⑤	99
B. 4. **Showering is:**	①	②	③	④	⑤	99
B. 5. **Light household chores such as tidying and dusting are:**	①	②	③	④	⑤	99
B. 6. **Gardening and yard work are:**	①	②	③	④	⑤	99

	This task is not applicable for me	Not at all difficult	A little bit difficult	Moderately difficult	Extremely difficult	Impossible to do
B. 7. **Preparing meals is:**	1	2	3	4	5	99
B. 8. **Going shopping is:**	1	2	3	4	5	99
B. 9. **Heavy household chores such as vacuuming and moving furniture is:**	1	2	3	4	5	99
B.10. **Getting in and out of the bath tub is:**	1	2	3	4	5	99
B.11. **Getting out of bed is:**	1	2	3	4	5	99
B.12. **Rising from a chair is:**	1	2	3	4	5	99
B.13. **Kneeling is:**	1	2	3	4	5	99
B.14. **Bending to pick something up off the floor is:**	1	2	3	4	5	99
B.15. **Walking upstairs is:**	1	2	3	4	5	99
B.16. **Walking downstairs is:**	1	2	3	4	5	99
B.17. **Driving is:**	1	2	3	4	5	99
B.18. **Walking in the house is:**	1	2	3	4	5	99
B.19. **Walking outdoors is:**	1	2	3	4	5	99
B.20. **Sitting is:**	1	2	3	4	5	99
B.21. **Walking up or down hills or a ramp is:**	1	2	3	4	5	99
B.22. **Standing is:**	1	2	3	4	5	99
B.23. **Getting up from kneeling is:**	1	2	3	4	5	99
B.24. **Getting in and out of a car is:**	1	2	3	4	5	99
B.25. **Participating in sexual activities is:**	1	2	3	4	5	99
B.26. **Completing my usual duties at work is:** (Work includes both a job outside the home and as a homemaker.)	1	2	3	4	5	99
B.27. **Working my usual number of hours is:** (Working includes both a job outside the home and as a homemaker.)	1	2	3	4	5	99
B.28. **Participating in my usual leisure activities is:**	1	2	3	4	5	99
B.29. **Socializing with friends and family is:**	1	2	3	4	5	99
B.30. **Participating in my usual sporting activities is:**	1	2	3	4	5	99

Please mark how you feel ("disagree," "no opinion," or "agree" about the following statements relating to how well you have adapted to others and your surroundings.

	Agree	No Opinion	Disagree
C. 1. **I move around my living quarters as I feel is necessary.** (Wheel chairs, other equipment or resources may be used.)	○	○	○
C. 2. **I move around my community as I feel is necessary.** (Wheel chairs, other equipment or resources may be used.)	○	○	○
C. 3. **I am able to take trips out of town as I feel is necessary.** (Wheel chairs, other equipment or resources may be used.)	○	○	○
C. 4. **I am comfortable with how my self-care needs (dressing, feeding, toileting, bathing) are met.** (Adaptive equipment, supervision, and/or assistance may be used.)	○	○	○
C. 5. **I spend most of my days occupied in a work activity that is necessary or important to me.** (Work activity could be paid employment, housework, volunteer work, school, etc. Adaptive equipment, supervision, and/or assistance may be used.)	○	○	○
C. 6. **I am able to participate in recreational hobbies (hobbies, crafts, sports, reading, television, games, computers, etc.) as I want to.** (Adaptive equipment, supervision, and/or assistance may be used.)	○	○	○
C. 7. **I participate in social activities with family, friends, and/or business acquaintances as is necessary or desirable to me.** (Adaptive equipment, supervision, and/or assistance may be used.)	○	○	○
C. 8. **I assume a role in my family which meets my needs and those of other family members.** (Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis. Adaptive equipment, supervision, and/or assistance may be used.)	○	○	○
C. 9. **In general, I am comfortable with my personal relationships**	○	○	○
C.10. **In general, I am comfortable with myself when I am in the company of others**	○	○	○
C.11. **I feel that I can deal with life events as they happen**	○	○	○

Please darken in the circle of the appropriate response to the following questions:

D1. **Considering all the activities in which I participate in daily life, I would rate the ability to perform these activities during the past week as:**

① impossible to do.
② extremely difficult.
③ moderately difficult.
④ a little bit difficult.
⑤ not at all difficult.

D2. **I would rate myself as being:**

① completely disabled.
② severely disabled.
③ moderately disabled.
④ mildly disabled.
⑤ not at all disabled.

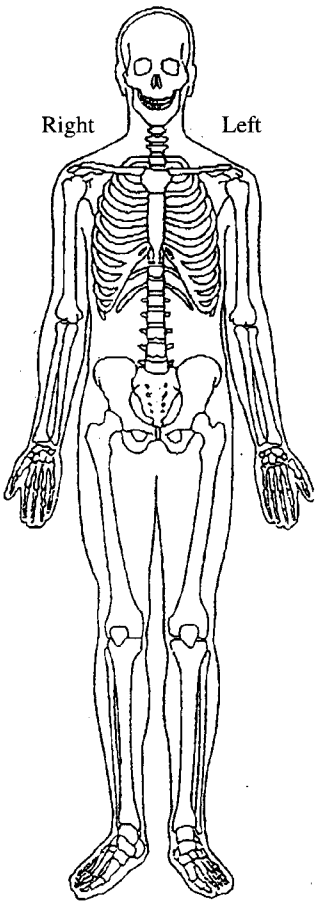
D3. **Describe the mobility or walking aid you use:**

① No aid
② One cane or crutch
③ Two canes
④ Two crutches
⑤ Walker
⑥ Wheelchair
⑦ Motorized wheelchair or scooter

D4. As you know, you were asked to participate in this study because you were treated for a bone cancer or tumor. Do you know where your tumor first started?

○ No
○ Yes

If yes, please **place one "X" on this skeleton** where the tumor was located.



Please make any additional comments about difficulties you experience below.

After completing this questionnaire, please return by using the enclosed envelope, and mail to:

Long-Term Follow-Up Study
Department of Pediatrics
University of Minnesota
420 Delaware St. SE, MMC 715
Minneapolis, MN 55455

Again, thank you for your help and your participation in this study!